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ABSTRACT

To investigate the process whereby families cope with the stresses associated with the decision to transfer their developmentally disabled relatives and are able to overcome their negative attitudes and feelings toward the relocation and the new facilities, 187 relatives (72% parents) of residents who were transferred were surveyed. The residents were moved from a large state institution to four smaller institutions closer to their families. The questionnaire assessed family involvement, stresses, feelings, policy knowledge, satisfaction with services, social support, coping, and family satisfaction. Social workers at the closing facility also completed a questionnaire assessing the degree of family involvement with the relative. An analysis of the results showed that the majority of families were very dissatisfied with the decision to close the institution, expressing concern for the negative impact of the move on the resident. The majority of respondents reported feeling stressed when they first heard about the closure; however, stress was decreased with time and information. Those with the greatest closure-related stress were those with worries about transfer trauma and those who had experienced high stress upon initial diagnosis and placement of their relative. Family dissatisfaction was correlated with worries about transfer trauma and meeting their relative's medical needs. Social support from new staff was most beneficial in reducing stress and increasing family satisfaction. The findings indicate that family opposition could be lessened if their concerns were addressed directly and their involvement elicited early in the closure process. (BL)

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FAMILY REACTIONS TO INSTITUTIONAL CLOSURE

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Family Reactions

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Investigators have documented strong family resistance to moving their developmentally disabled relatives out of large state institutions into the community or other institutions (Conroy & Latib, 1982). However, little research has been done to determine the impact of the residential transfers on the families or to describe the process whereby the families deal with their relatives' relocation. That is, what personal characteristics contribute to a family's adaptations to such changes? The closure of a large Illinois institution for developmentally disabled individuals has provided us with a unique opportunity to study these issues.

Surveys conducted in several states (Washington, Pennsylvania, New Jersey) revealed that approximately two-thirds of the families of institutionalized mentally retarded people opposed community placements for their relatives (Landesman-Dwyer, 1981). In some cases, such as in Illinois, families have sued the state to prevent institutional closures.

This opposition centers around perceptions that the large institutions provide better care, more experienced staff, and greater stability for their relatives than would other smaller or community-based facilities (Payne, 1976). Family members are particularly concerned that the new facilities will not be able to meet their relative's medical needs. In fact, those family members who perceive their relative's medical needs as serious, are more negative to deinstitutionalization (Keating, Conroy & Walker, 1980). Even those families who are dissatisfied with the care and programming at the institutions appear just as likely to choose the institution as the preferred placement as are those who are satisfied (Meyer, 1980).

Families also have concerns about the normalization and developmental ideology underlying the alternative community-based services, the process utilized to implement closures and transfers, and their own ability to cope with their relative in the community (Frohboese & Sales, 1980).

For many families deinstitutionalization and/or residential relocation of their relative presents a crisis situation. Crisis theory suggests that a crisis occurs when an individual or family encounters an abnormal and unexpected event (Jordan, 1962) which appears to have no immediate solution and leads to disruption of the usual coping mechanism (Caplan, 1964). In a study of 43 relatives of transferred mentally retarded people, nearly half of the families reportedly experienced a crisis when their relative was deinstitutionalized (Willer, Intagliata, & Atkinson, in press). The researchers suggested that family reactions to this event are predictable on the basis of how the family managed other crisis periods, such as diagnosis and institutionalization. Frequently the families most opposed to transfer of their relative out of the institutions are those who experienced higher stress when initially making the decision to institutionalize their relative (Conroy & Latib, 1982). Carver and Carver (1972) report that most parents experience intense guilt and a sense of failure following their decision to institutionalize an offspring. Stedman (1977) has advanced the notion that in most cases deinstitutionalization entails a "painful reversal and revisitation" of the institutionalization decision. Hence for many families, impending transfers of their relatives can give rise to feelings of anger, guilt, confusion, and fear of the "unknown".

Interestingly, several studies have noted that families' views

dramatically change after the transfers, with very few reporting negative feelings about the placement outcome for their relatives (Landesman-Dwyer, 1981). Rather, the majority report satisfaction with the quality and benefits of services, more positive attitudes towards deinstitutionalization, and increased general happiness of their transferred relatives (Conroy & Latib, 1982).

These findings indicate that family attitudes can be changed when the fears of the "unknown" are alleviated and there is a realization that the new facilities provide adequate care.

This study examines the process whereby families a) cope with the initial stresses brought about by the decision to transfer their retarded relatives and b) change their attitudes and feelings towards the relocation and the new facilities. Lazarus's (Lazarus, 1966) cognitive-phenomenological analysis of the psychological stress provides the theoretical framework for studying this process. People vary widely in how they cope with stresses and how they utilize their social support networks during crisis situations. Although there is a growing conviction that the ways people cope with stress affect their psychological and physical well-being, little is known about how coping and social support play mediating roles in alleviating stressful situations. Lazarus theorizes that the degree to which a person experiences psychological stress---that is feels harmed, threatened, or challenged---depends not only on the objective situation, but also on one's evaluation of what is at stake and the evaluation of coping resources. Coping is defined as "the cognitive and behavioral efforts made to master, tolerate, or reduce external and internal demands and conflicts among them." (Folkman &

Lazarus, 1980, p. 223). Coping strategies serve two major functions: the alteration of the person-environment relationship that is the source of stress (problem-focused coping) and the control of stressful emotions (emotion-focused coping). People are more likely to use problem-focused methods when they perceive the possibility of beneficial changes and when they feel that something constructive can be done. It seems likely that families that utilize problem-focused coping strategies and who receive social support from the people around them will adapt better to the stress of their relative's relocation. Three major questions are addressed: What factors account for family opposition to relocating their relative? What impact does the relocation have on the families? What role do personal coping strategies and social support networks play in mediating this impact?

Methodology

Subjects

The family sample includes 187 relatives of residents who were either transferred after November 1982 or about to be transferred out of a large state institution for developmentally disabled adults, which was about to close, into four smaller institutions closer to their families.

Seventy two percent of the sample were parents of the developmentally disabled individuals, 20 percent were siblings and 8 percent were other relatives or close nonrelative friends. Seventy four percent of the respondents were caucasian, 17 percent were black, 6 percent were hispanic, .5 percent were American Indian, 0 percent were of Asian

descent, and the remainder classified themselves as "other". The incomes of participants ranged from under \$10,000 to over \$50,000 with 47 percent of the sample earning less than \$10,000 and 36 percent earning between \$10,000 and \$30,000. The education level of respondents also covers a broad range from "no formal education" to "post graduate work". The majority of respondents (6 percent) have no more than a high school education.

This study is part of a three year project also investigating the impact of the closure on the residents and employees. The institution was located in a rural small town in Illinois and housed 823 residents of which 80 percent were profoundly retarded. The closure of the institution was heatedly opposed by both the employees and the families of the residents. In fact, the parent association initiated a lawsuit to prevent, or at least to modify the facility closure. They succeeded in delaying the transfers for many months and in influencing transfer proceedings.

In January and February 1983, questionnaires were sent to 345 families. Of these 187 were returned, which resulted in a response rate of 54 percent. The questionnaire included the following types of items and scales: 1) demographics, 2) degree of family involvement with the client and the transfer process, 3) stresses and feelings experienced by the families, 4) knowledge about closure policies and procedures, 5) satisfaction with facility services, the closure decision, and the transfer process, 6) ideology and philosophy of care, 7) feelings about the transfer and the new facility, 8) social support, 9) coping strategies utilized, and 10) family and life satisfaction. Several of the items were

adapted from questionnaires developed by Conroy and Latib (1982) and Willer et al. (in press).

Additionally, the social workers at the closing facility filled out a six-item questionnaire on the degree of family involvement with their relative and the closure process. Pearson correlations of the family and social worker ratings on the two items that were on both questionnaires, frequency of family visits to the institution before the closure announcement and frequency of family visits after announcement were .72 and .69 respectively, indicating high concordance between the family and social worker ratings.

Results

General Approach to Analyses

Some of the results to be presented are straight forward summary statistics on particular questionnaire items. However, to address some of the more subtle issues surrounding the opposition to and the impact of the relocation, regression analyses were done. For those analyses, questionnaire items and social worker ratings were first organized into factors in order to reduce all the information into understandable scales and to reduce the intercorrelations between measures. Scores on these factors were entered into the regressions.

Factor analyses were done separately on predefined groups of questions which tap: 1) descriptive characteristics 2) coping styles/approaches and 3) outcome attitudes, impact of closure and life satisfactions. These factor analyses yielded eight descriptive factors:

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1. Socioeconomic status of family
2. Race of family
3. Degree of family involvement with relative prior to transfer
4. Amount of stress experienced by family upon initial diagnosis and placement of relative
5. Severity of resident's medical problems
6. Satisfaction with services offered at the old facility
7. Family attitudes about the effects of transfers on residents
8. Family beliefs about treatment ideology for developmentally disabled individuals

Eight coping factors emerged -- three related to social support and three related to specific coping styles and two related to how they found out about the closure. The social support factors are 1) informal supports (eg. from spouse/ partner, relatives, friends, other parents, or professional service providers), 2) support from the old facility staff and parent association, and 3) support from the staff of their relative's new facility. The coping factors are: 1) problem solving (e.g., "stood your ground and fought for what you wanted"), 2) wishful thinking (e.g., "wished the situation would go away and somehow be over with"), 3) emotional (e.g., "Got professional help and did what was recommended," "Got away from it for a while"). The two factors related to how the families found out about the closure were 1) whether they heard through a rumor or other informal channels, like other parents or staff and 2) whether they received an official letter announcing the closure decision.

The outcome variables fell into three factors:

1. Satisfaction with the closure decision and process
2. Stress experienced during the closure and transfer processes
3. Satisfaction with services at the old facility after the closure was announced

Family Satisfaction and Attitudes

Most relatives in this study were satisfied with the services offered at the old facility over the last five years (94%) and a slightly smaller percent were satisfied with services offered at the old facility after the closure was announced (85 percent). Relatives were asked to rate their satisfaction on a four point scale from "very dissatisfied (rated 4) to "very satisfied" (rated '1'). The mean for satisfaction with services over the last 5 years was 1.46 (s.d.=.69) while the mean for satisfaction with services offered since the closure announcement was 1.64 (s.d.=.88).

Families were, by and large, very dissatisfied with the decision to close the institution. Seventy five percent of the families reported they were either slightly or very dissatisfied and the mean rating across families on a four point scale similar to the one described above was 3.16 (s.d.=1.06). Families were somewhat less critical of the way in which the transfers were being carried out; only 30 percent of the families were dissatisfied with the transfer process itself and the mean satisfaction level across families was 2.10 (s.d.=1.13). See Table 1 for a summary of these results.

The families involved in this study tend to feel that their relative has reached his/her highest level of development (79 percent), and they prefer that their relative remain in one placement for his/her entire lifetime (86 percent). Fewer families, although still a majority (63

percent), agree with the normalization philosophy, and only a small percent (17 percent) feel that their relative would benefit from a community placement.

Most of the families felt that their relative would be harmed by changes in his/her relationships with staff and other residents (75 percent) and that transfers from one institution to another typically have a negative impact on residents (79 percent). These results reflect the high percent of families that feared the negative impact of the relocation process.

The families vary somewhat on their expectations of future services for their relative after the transfer. Only a little over half of the families think the new facilities will be able to house the transferees without overcrowding (56 percent). Most families report being confident that the staff of the new facilities will be skillful enough to deal with their relative (87 percent), that the funding for the new facility is secure (72 percent) and that all needed services will be available (83 percent). (See Table 2)

Impact of Relocation on Families

To put some of these results into context, it is interesting to note that there were no significant differences between the pre and post move families with respect to the emotions they experienced when they heard about the closure.

The impact of the relocation on these families is also reflected in the levels of stress they report for specific events associated with the closure and relocation. Seventy seven percent of the families report feeling stressed when they first heard a rumor about the closure of the

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facility, 75 percent when they heard the official announcement of the closure, 53 percent when they received an official letter about the closure, 43 percent when they sought more information about the closure and relocation process, 25 percent when they heard about the actual placement decision for their relative, and 20 percent when they first visited their relative's new facility.

Families rated the amount of stress they experienced during each event on a five point scale (1 = "extremely stressful"). The mean level of stress reported for these events are as follows:

	$\bar{X}$	s.d.
1. heard rumor about closure	1.83	1.20
2. heard official announcement about the closure	1.94	1.41
3. received an official letter about the closure	2.53	1.41
4. sought more information	2.89	1.45
5. heard actual placement decision	3.6	1.45
6. visited relative's new facility	4.09	1.25

These results indicate that many families experienced considerable stress with the closure and transfer process, and that both the percent of families and the mean level of stress reported go down over the series of events.

The families were asked to describe the feelings they had 1) when they first heard about the closure and then 2) at the time they filled out the questionnaire. The results are as follows:

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	when first heard	now
surprised	58%	15%
disbelieving	30	13
afraid	33	18
depressed	31	18
angry	41	31
optimistic	8	17
relieved	2	15
accepting	20	51

The differences between the responses of those families with relatives who had not moved prior to their answering the questionnaire (n=120) and those families whose relative had already moved (n=55) were a preliminary source for discovering the impact of the relocation on the families. Data regarding pre/post status was missing on 12 of the families. A two variable model was found to account for a significant amount of the variance between the groups ($R^2 = .195$, $F(2, 172) = 20.82$, $p < .001$). The families whose relative had already moved were feeling more general positive emotions at the present time and were feeling more positively about the decision to close the large institution. (See Table 3)

There are two other variables that do not add to the predictive ability beyond the two initial variables, but do reflect additional differences between the pre and post move families. The post move families are feeling fewer negative emotions now than the premove

families, and they are less critical of the whole idea of transfers and relocation of institution residents.

Determinants of Family Reactions to Closure and Relocation

A series of regression analyses were done to assess what family characteristics determine their reaction to the closure. Three outcome variables were defined 1) satisfaction with services offered at the old facility following the closure announcement, 2) satisfaction with the closure decision and the relocation process and 3) the degree of stress experienced by the family during the closure/relocation.

A five variable model accounts for a significant amount of the variance in satisfaction with services since the closure announcement ($R^2 = .43, F(5,181) = 27.4, p < .0001$). Race involvement with relative, satisfaction with services at the old facility over the last five years, and feelings about the future all significantly contribute to the predictive ability of the model. In sum, minority families who have been more involved with their relatives, and who not only have been more satisfied with the services at the old facility over the years, but who also are more optimistic about future services, are more likely to be satisfied with the services since the closure.

The major predictors of satisfaction with the closure are the family's beliefs about the effects of transfers on residents, the family's involvement with their relative, and the severity of the resident's medical problems. The families who are most satisfied with the closure decision 1) do not feel the transfer will have a negative impact, 2) are less involved with their relatives and 3) have relatives with less severe medical needs ($F(3,183) = 27.69, p < .0001$).

Three factors emerge as significant predictors of the amount of stress experienced by the families ($R^2 = .32$, $F(3,183) = 28.27$, $p < .0001$): 1) the family's beliefs about the negative impact of transfers, 2) the severity of the developmentally disabled relative's medical problems, and 3) the amount of stress the family experienced when they initially heard about their relative's condition and when the relative was initially placed. It appears that families who are worried about the negative impact of the transfer, who have relatives with more severe medical problems, and who experience more early stress with their mentally retarded relative, were the families who experienced the most stress during the closure and relocation process.

Social Support and Coping

Stepwise regressions were done to assess the degree to which either social support or specific coping strategies mediate the outcomes of stress or satisfaction with the closure. Only one mediating variable added significantly to the prediction of either of the outcomes.

The amount of support a family member received from the staff of their relative's new facility added significantly to the prediction of satisfaction with the closure decision. It also reduced the predictive contributions of all three other predictive variables (i.e., worry about transfer, severity of resident's medical problems, and involvement with relative). These results imply that social support from new staff is part of the reason for the relationship between the initial predictors and satisfaction. It appears that the more social support families receive from the new staff, the more satisfied they are with the closure.

Family Involvement in Court Action

In order to answer the question about what factors account for family opposition to relocating their relative, regression analyses were done to determine what demographic, ideological, attitudinal or experiential characteristics predict involvement in the court action.

Five variables emerge as significant predictors. The families involved in the court action tend to 1) be more involved with resident, 2) receive more special support from the old facility staff, 3) have heard about the closure through early rumors or from informal contacts (ie., old facility staff, Parent Associations), 4) have experienced more stress upon initial life experiences with relative, and 5) have received an official letter from the facility about the closure. This five variable model yields an R^2 of .377 ($F(5,137) = 16.55, p < .0001$).

Even though they did not add in significantly to the regression, t tests indicate some significant differences between those involved versus not involved in the court action. Families involved in the court action tend to be less satisfied with the services offered at the old facility after the closure announcement ($t(23) = 2.99, p < .007$), to have employed more problem solving coping strategies during the closure/transfer process ($t(29.5) = -3.29, p < .003$) and to have experienced more stress during the closure/transfers ($t(57) = -3.57, p < .001$). (See Table 4)

It is interesting to note that those involved in the suit are no different from other families in terms of their socioeconomic status, their beliefs about treatment approaches or the general impact of transfer, or their satisfaction with services at the old facility over the last five years.

Discussion

During this institutional closure families overwhelmingly opposed transfers of their developmentally disabled relatives out of a large state institution into smaller ones closer to their communities. As in the previous studies, families were generally satisfied with previous services offered at the institution and were fearful of residential transfers. Over three fourths of the families felt that their relatives would be harmed by the disruptions surrounding the actual relocation. Hence, it seems that most families would have preferred to avoid the process of change.

Although the majority of the families agreed with the general benefits of home like environments, they disagreed with the underlying assumptions of the normalization and developmental concepts. For example, only 17 percent of the families felt that their relative would benefit from a community placement. This may have contributed to their earlier preference for the large state institution.

With the exception of some fears of over crowding at the new facilities, the families were generally confident about the services and staff at the new facilities. This indicates that their fears were mostly focused not on the changes in the residential environments and programs but on what would happen to their relative during the move itself. Families' confidence in the new facilities may be related to the fact that in this institutional phasedown, the transfers were to similar types of facilities, rather than to more alternative community-based facilities.

Moreover, although the families strongly resisted the closure decision, only 30 percent were dissatisfied with the closure process that transpired. This low level of dissatisfaction could be attributed, at least in part, to the elaborate transfer proceedings set up by the state ostensibly in response to the plaintiff's court action.

The closure rumors and announcement seem to have had profound effects on the families with over three fourths reporting high stress when they first heard about the closure. Over time, the stress levels decreased with about half of the families reporting stress at the time of the official closure letter and less than one fourth reporting stress at the times of the placement decision and visits to the new facilities. As the novelty and initial shock wears off and as the families receive more information about the closure process and the new facilities, much of the stress seems to become defused. This seems particularly evident in the comparisons of the families whose relatives already transferred (post move) with those whose relatives were still at the old institution (pre move). Post move families expressed more positive emotions (optimism, relief, acceptance), less fearfulness about the impact of transfers, and greater satisfaction with the closure. This finding concurs with previous results from other studies (e.g., Landesman-Dwyer, 1981) showing considerable attitude change among families following transfers out of institutions.

The families who revealed the greatest amount of closure-related stress are those who are most worried about the "transfer trauma" and who experienced high stress upon the initial diagnosis and institutional placement of their relative. They are not necessarily people who are more

involved or visit more with their relative. This provides some support for Stedman's (1977) notion that for many families transfer of their relative out of an institution rekindles the feelings associated with the initial decision to institutionalize their relative. It is interesting to note that no one specific type of coping strategy seems to mediate the stressful impact of the closure on the families.

Similarly, the families dissatisfied with the closure also tend to be ones worried about "transfer trauma" and about meeting their relative's serious medical needs. The families most opposed to closure also tend to be the ones most involved with their relatives. Satisfaction with the closure decision seems to be mediated by social support from the staff of the new facilities. Apparently, as the families increase their contacts with the new staff, their concerns about their relative's medical problems and reactions to transfer are less likely to lead to dissatisfaction with the closure. Similarly, one might postulate that employing "buddy systems" linking receiving facility families with phasedown families may also reduce the latter's dissatisfaction level.

Nearly 15 percent of the families sampled in this study were involved in the lawsuit. These families tended to be the ones who experienced more stress with their relative's initial diagnosis and institutional placement, were more involved and had more contact with their relative and tended to use problem solving coping strategies. This provides us with a picture of people who have a positive investment in their relative and who actively seek to have a voice in their relative's habilitation and training. Since these people had considerable contact with the staff at the old institution and tended to receive more support from them than did

those families uninvolved in the court action, it seems important to understand the role of the staff in encouraging the suit. When employees are upset about phasedown, staff and parents may likely join forces in adversarial confrontations with the state, particularly in the absence of alternative social supports.

Study findings point to the importance of alleviating family anxieties about "transfer trauma" and about the adequacy of medical care in the new facilities. Family opposition would probably be lessened considerably if their concerns were addressed directly and their involvement elicited early in the closure process. They would benefit from receiving early clear cut information on the transfer process and the new facility. In particular, the staff at the new facility can play a significant role in allaying the fears of the families about impending transfers.

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TABLE 1

FAMILY SATISFACTION

- a. How satisfied have you been with the overall services at DDC over the last five years?

very satisfied 63%
 somewhat satisfied 31
 somewhat dissatisfied 4
 very dissatisfied 2

- b. How satisfied have you been with the services provided at DDC since the closure was announced?

very satisfied 57%
 somewhat satisfied 29
 somewhat dissatisfied 8
 very dissatisfied 6

- c. How satisfied are you with the decision to close DDC?

very satisfied 12%
 somewhat satisfied 14
 somewhat dissatisfied 21
 very dissatisfied 53

- d. How satisfied are you with the way the transfers are being carried out?

very satisfied 40%
 somewhat satisfied 29
 somewhat dissatisfied 12
 very dissatisfied 19

TABLE 2

FAMILY BELIEFS

<u>Treatment Ideology:</u>	<u>% Strongly Agree</u>	<u>% Somewhat Agree</u>	<u>% Somewhat Disagree</u>	<u>% Strongly Disagree</u>
a. My relative has reached his/her highest level of development and will not progress much beyond the level he/she is at now	43	36	15	6
b. When my relative lives away from home, I prefer that he/she remain in the same place for his/her entire lifetime	61	25	8	6
c. My relative would benefit from living, working, and going to school in places which are as much like normal as possible	40	23	10	27
d. My relative would benefit from a move out of an institution and into a community placement	9	8	12	71

Feelings About the Transfer:

a. My relative will be harmed by changes in his/her relationships with familiar staff and other residents	36	39	18	7
b. Transfers from one institution to another have a negative impact on residents	49	30	17	4

Expectations of Future Services:

a. The receiving facilities will be able to house the Dixon transferees without overcrowding	27	29	26	18
b. Persons who work in my relative's new facility are knowledgeable and skillful enough to deal with my relative	51	36	5	8
c. Funding for my relative's new facility is secure and permanent ..	40	32	13	15
d. All services needed by my relative will be available to him/her in the new facility	46	37	11	6

TABLE 3

DIFFERENCES BETWEEN FAMILIES OF PRE AND POST TRANSFER RELATIVES

R square = .195			
	DF	F	Prob
Regression	2	20.82	0.0001
Error	172		
Total	174		
	B Value	F	Prob
Positive feelings now	-0.11067592	6.18	0.0139
Satisfaction with closure decision	-0.15285253	17.73	0.0001

TABLE 4

PREDICTIONS OF INVOLVEMENT IN COURT CASE

R square = .377			
	DF	F	Prob
Regression	5	16.55	0.0001
Error	137		
Total	142		
	B Value	F	Prob
DDC staff and parent support	-0.43120184	11.11	0.0011
Informal closure information	-0.33466736	9.23	0.0029
Formal closure letter	0.48458709	6.17	0.0142
Involvement with relative	-0.49365475	31.30	0.0001
Stress history	-0.22415276	5.52	0.0172